Personal Health Records: Personal Control of Health Data and Patient-Provider Communications

Second in a 3-part Series

April 3, 2008

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Agency for Healthcare Research and Quality

Patient Gateway: A Secure Patient Portal at Partners Healthcare

Presented by:

Jonathan Wald

Partners Healthcare

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Outline

- **Patient Gateway**
  - Description
  - Demo
  - Adoption
- **The Prepare for Care study:**
  - Diabetes RCT sub-study
    (Blackford Middleton, PI; Jonathan Wald, Co-PI)

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What is Patient Gateway?

- **A secure web application developed at Partners Healthcare**
  - Offered by over 800 providers in 42 primary and specialty care practices at 4 institutions (March, 2008) to patients
    - Massachusetts General Hospital, Brigham and Women's Hospital, Newton Wellesley Hospital, and Dana Farber Cancer Institute (a Partners Affiliate)
  - Linked to the LMR (Longitudinal Medical Record)

- **A patient portal – free to the patient**
  - Chart information – from the LMR/clinical systems
    - Medications, Allergies, Immunizations, future and past appointments
    - Lab Results (about 50 expanding to 200 in Spring 2008)
  - Online communication (web messaging) tied to practice workflow
    - Patient messages routed to practice staff for triage/handling (not physicians)
    - E.g. "Medication Desk"; "Appointment Desk"; "Message Desk"
    - Appointment reminders and message notifications (via Email)
  - Reference information – Healthwise®, plus contextual links to other web resources

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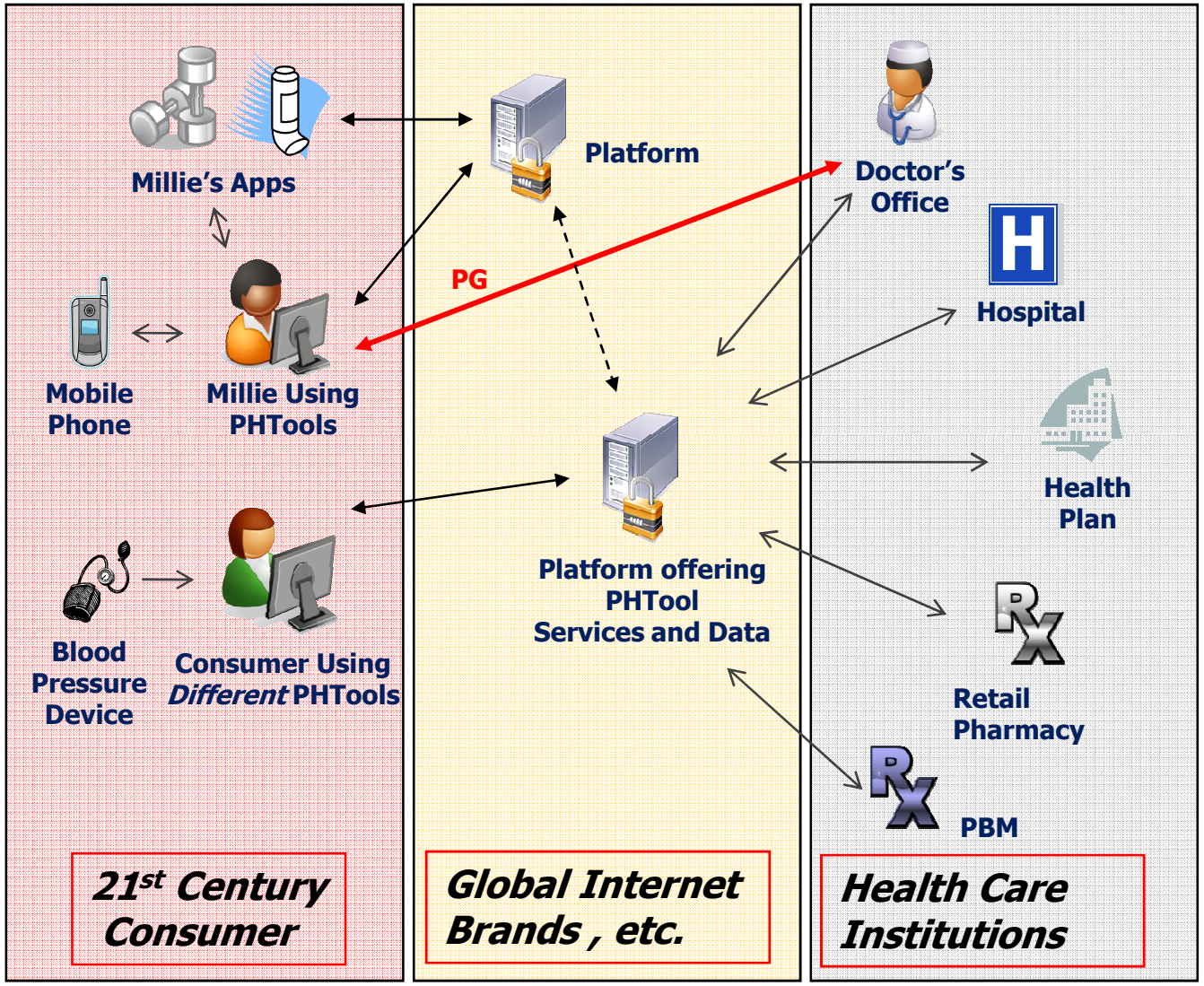
What is Patient Gateway (cont'd)?

- **A practice/provider portal**
  - Integration with LMR (PG account status, Save as note, Results Letter, etc)
  - Supports management of messages, Rx, appointments, referrals, etc.

- **A support portal**
  - Account creation, password distribution and recovery, detailed account information, issue handling, audit reports, software configuration, notifications, web content, etc.

Evolving personal health ecosystem



Why does Partners offer this?

- **Patient experience**
  - Service convenience
  - Shared medical information
  - Ease of communication with the practice
  - Strengthen patient-practice engagement and loyalty
- **Practices striving to be more productive**
  - Seamless patient/staff communication
  - Self-documenting requests
  - Time-efficient provider workflow
- **To support quality of care improvements**
  - Medication safety
  - Chronic care management and continuity of care
  - Patient activation and knowledge
  - Better adherence to plan of care

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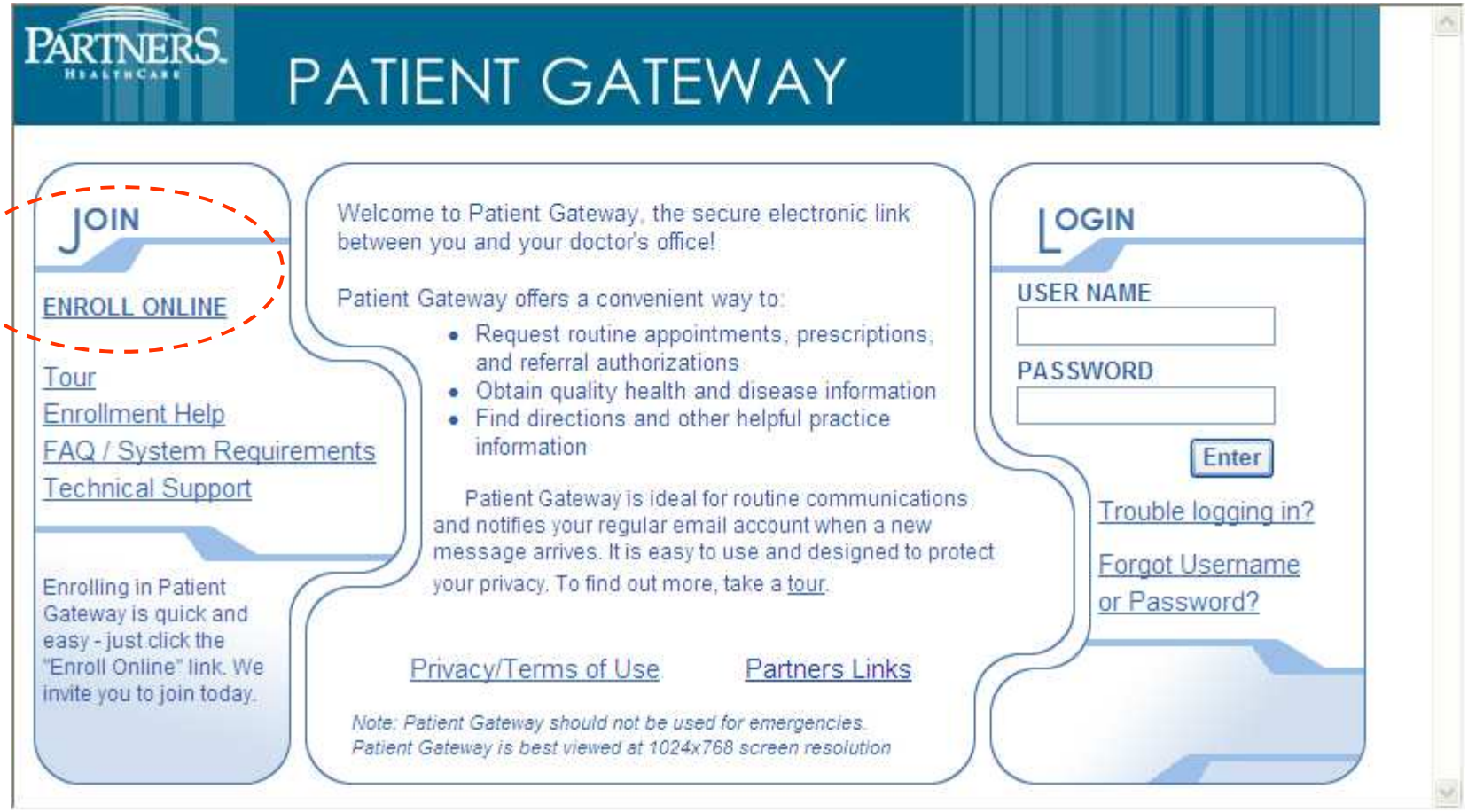
Patient Gateway Web Site

Available at: www.patientgateway.org



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Enrollment staff: Create New Account

1. **If request (left) matches a Partners Patient (right)**

Comparison Chart for Enrollment Request: 32904, Patient
Practice: Christina Iacobo M.D., Brigham and Women's Physician Group

Demographic Data	From PG Enroll	From EMPI Detail
Last Name	FakeLastName	FakeLastName
Middle Init		
First Name	KATE	KATE
Gender	F	F
DOB	03/01/1972	03/01/1972
Street Address	15 CONCORD STREET	15 CONCORD STREET
City	FakeCity	FakeCity
State	MA	MA
Zip	02999	02999
Home Phone	422-580-0099	422-580-0099

2. **PG account is created (Or, registration staff contacts pt)**
3. **Username (via email) & Password letter (via mail)**

Username (email) + **Password (postal mail)**

Patient: Welcome Screen

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Caregivers: Select a patient[1]

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Welcome, BE11

PATIENT GATEWAY

Home | Logout | Account | Support

Select Patient | Help

Please select a patient.

Continue only if you are authorized to use the health record of the patient you select. Otherwise, please contact support.

Patient List

Name ▲	DOB	Unread Mail	Future Appts.	Alerts
Eight Bwhpgtest	07/01/1929	1		1
Mary Bwhlmrtest	10/01/1951			1
Six Bwhlmrqatest	05/03/2005			2
Ten Bwhlmrqatest	05/03/2005			1

[1]*In pilot, March 2008*

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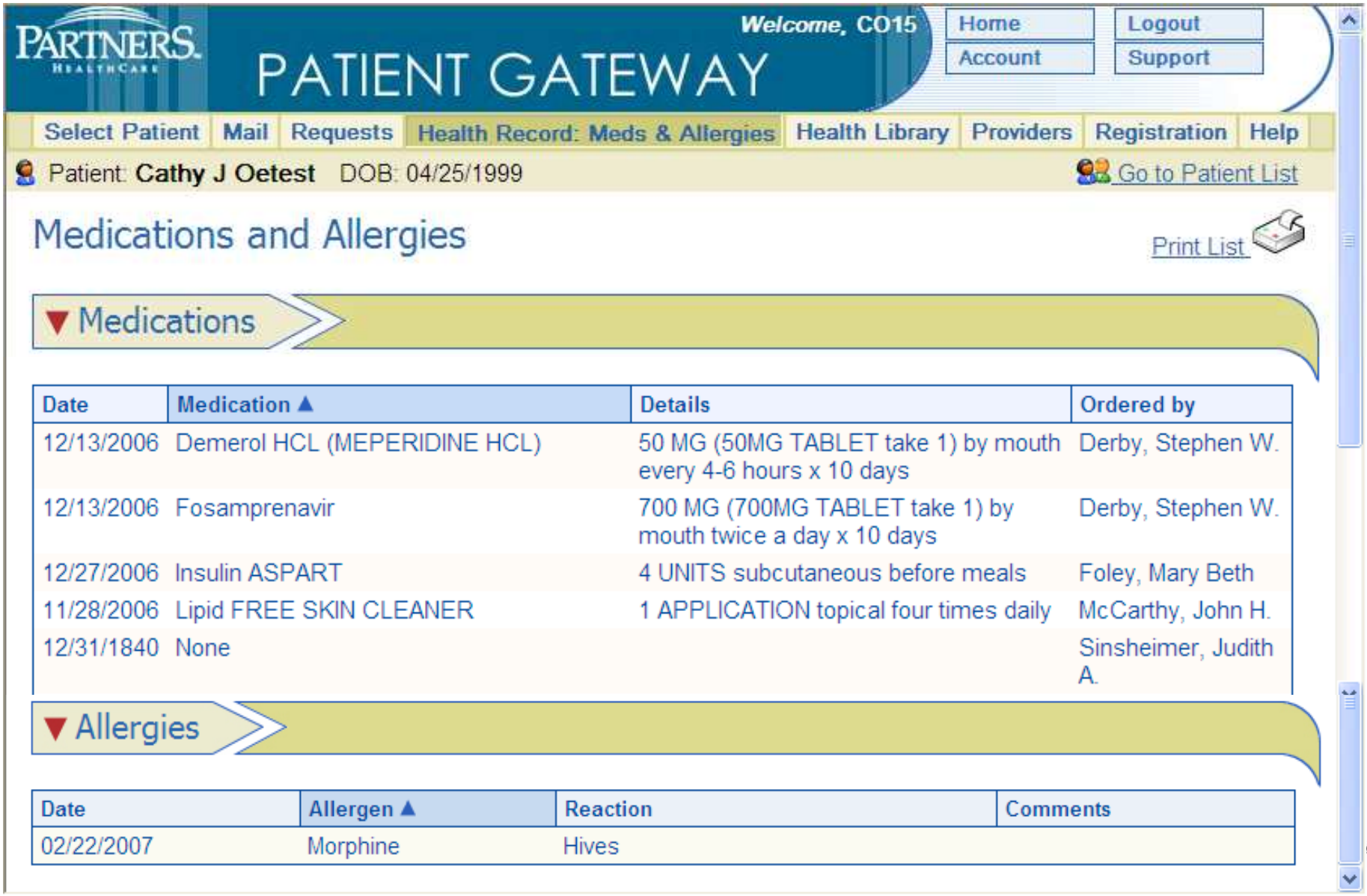
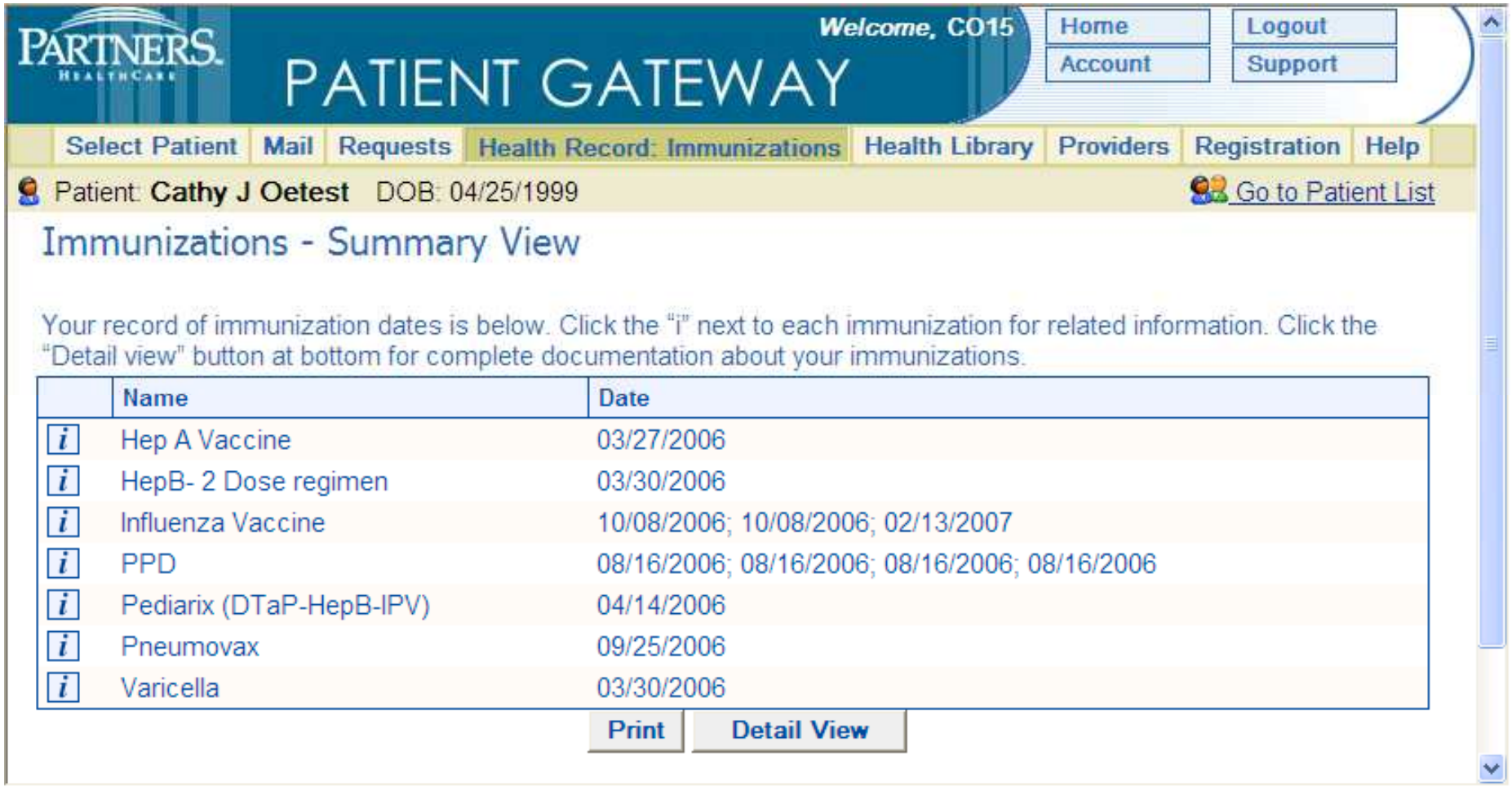
Medications & Allergies



Immunizations



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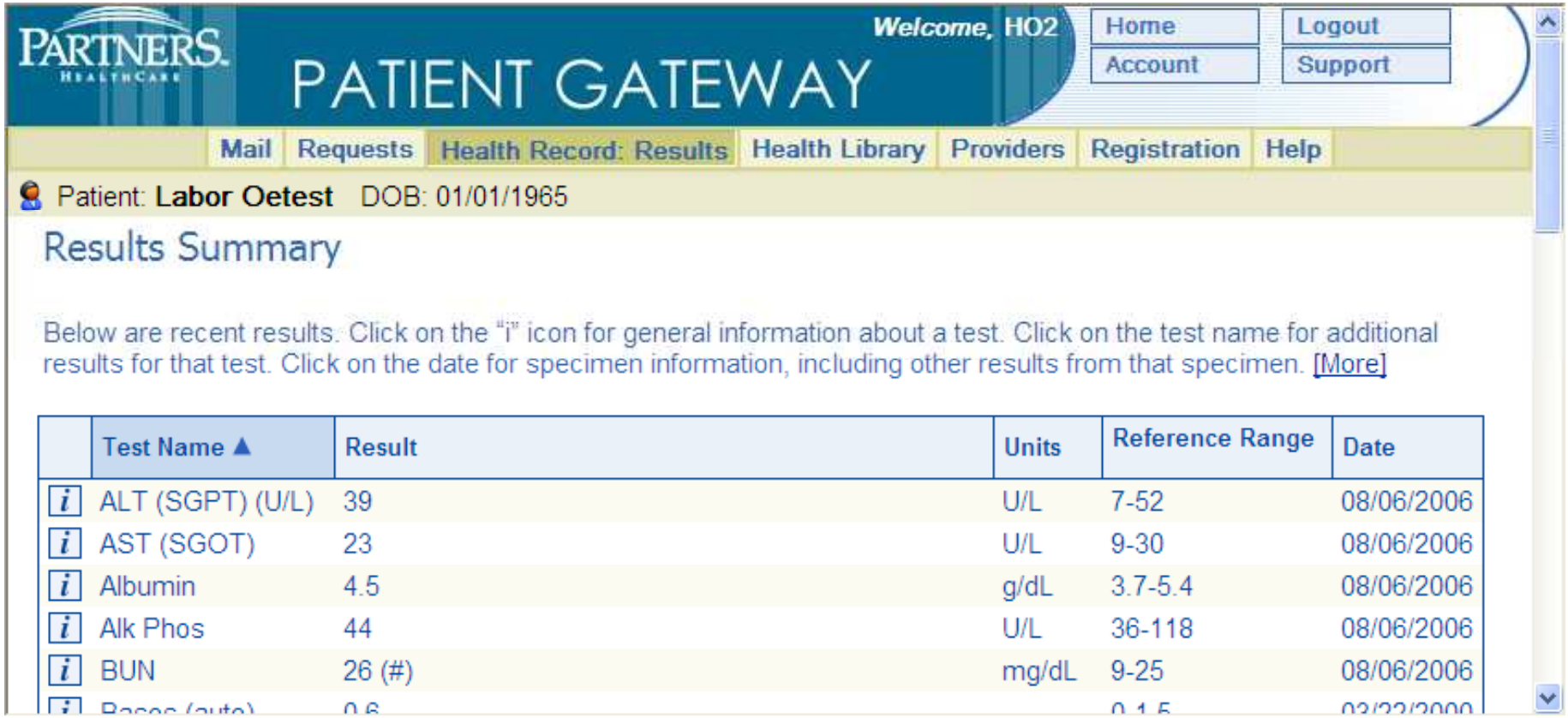
Lab Results



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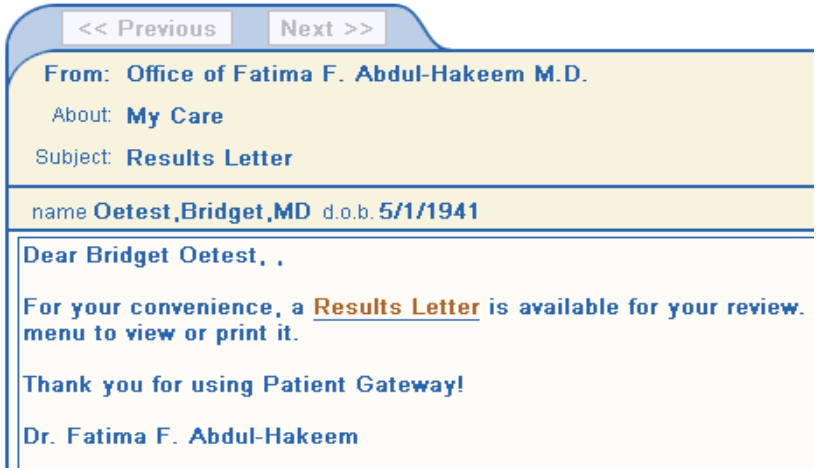
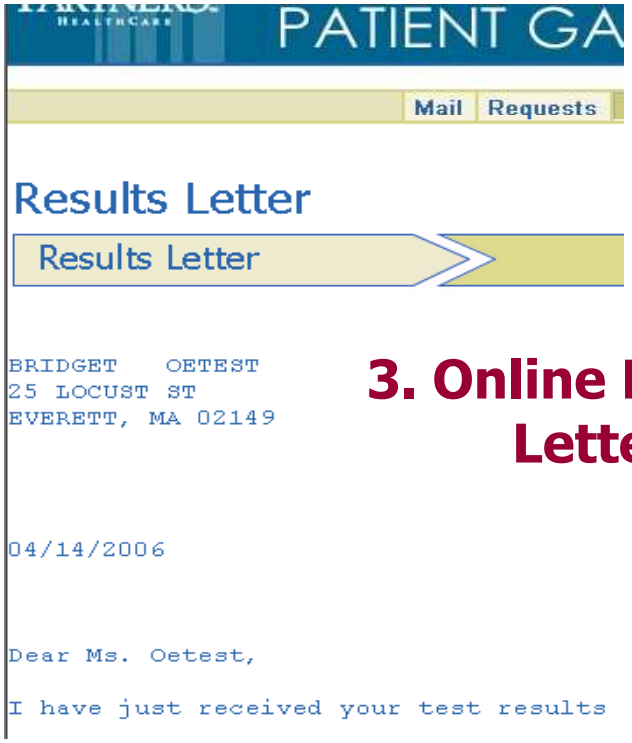
Online Results Letter

1. Notification
(email)

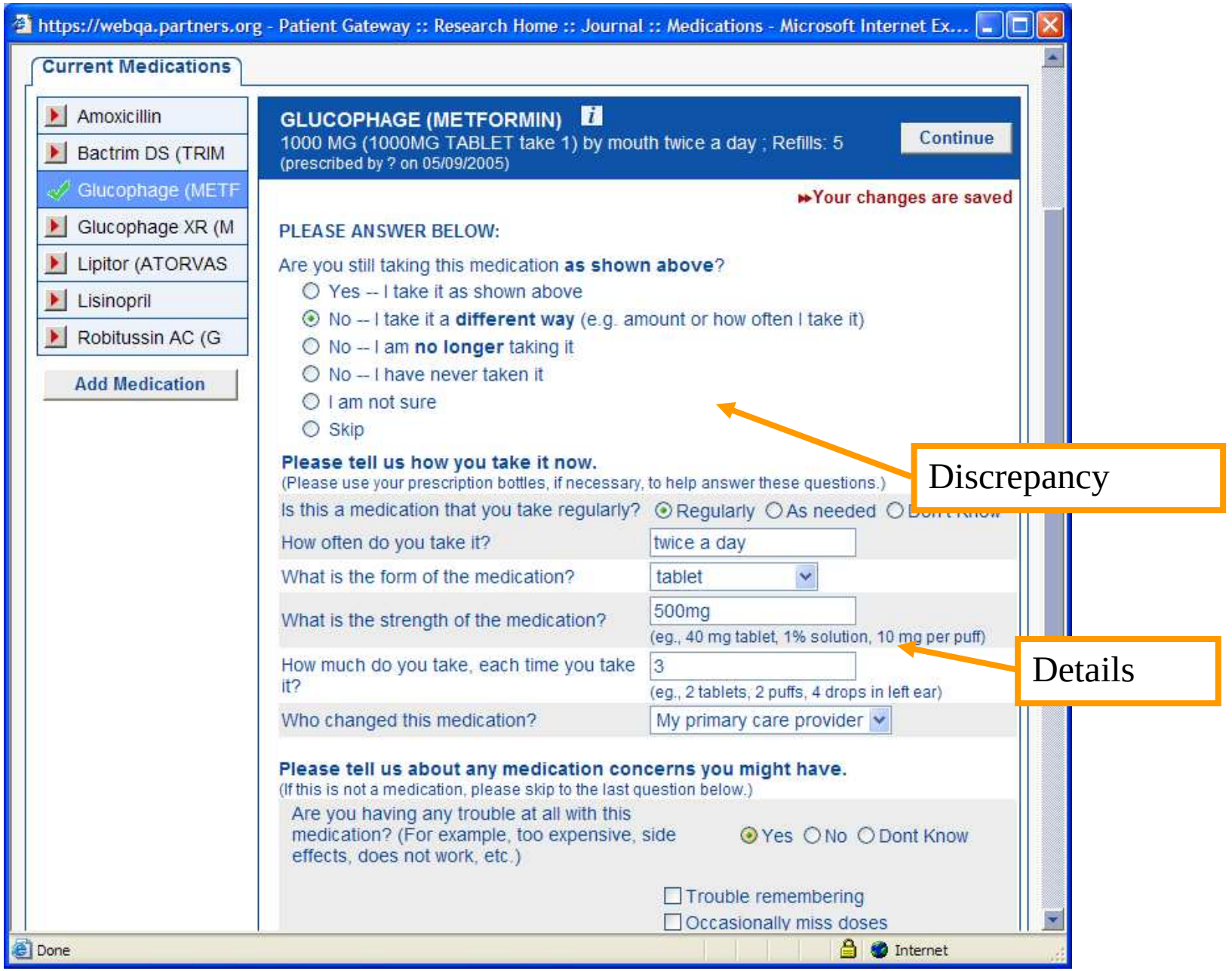


2. PG Message or Menu



3. Online Results Letter

Online Journal – *Prepare for Care study*



Practice Portal: *Message mgt*

<u>Incoming Requests</u>:

- ***Bolded***
- ***Provider identified***
- ***1-click to LMR***
- ***Click-sign to save as note***

<u>Sort by any column</u>:

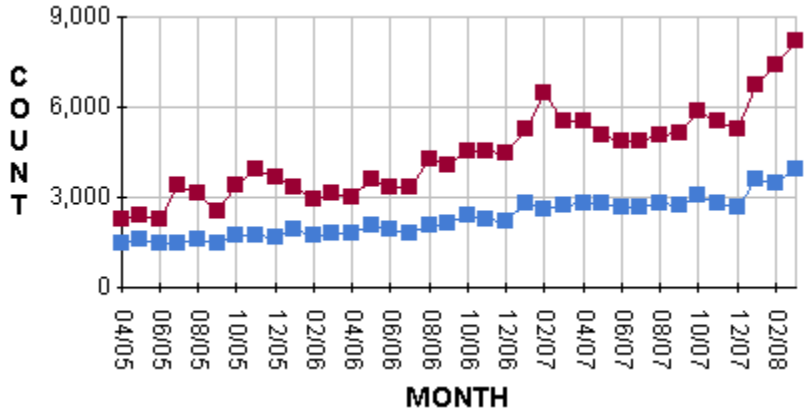
- ***Date***
- ***Provider***
- ***Patient***
- ***“Assign”***

Current status (March, 2008)

- **42 practices are live at Brigham & Women's Hospital, Massachusetts General Hospital, and Dana Farber Cancer Institute**
  - 23 primary care, 19 specialty care
  - Practice penetration as high as 63%
- **680 physicians are listed as providers for PG**
- **42,000+ patient accounts on PG**
  - Adding 1000/mo; 67% of accounts are "activated'
- **Over 8,100 patients used PG in the month of March, 2008**
  - 9.3 requests/100 pts/month

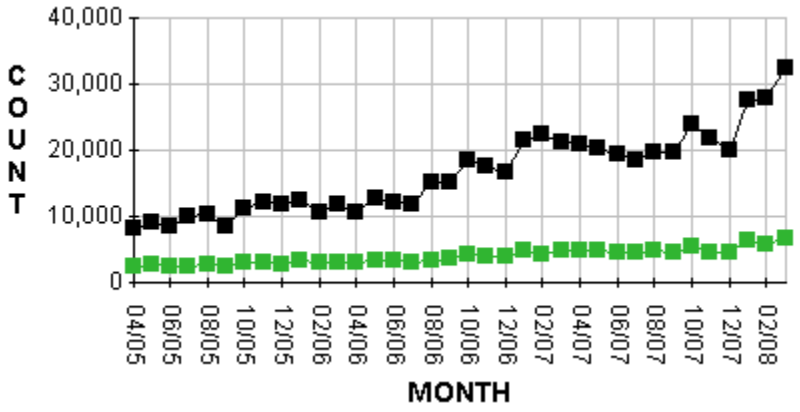
Unique Pts – Mar '08

- **8,157 patients who logged in**
- **3,896 patients with requests**

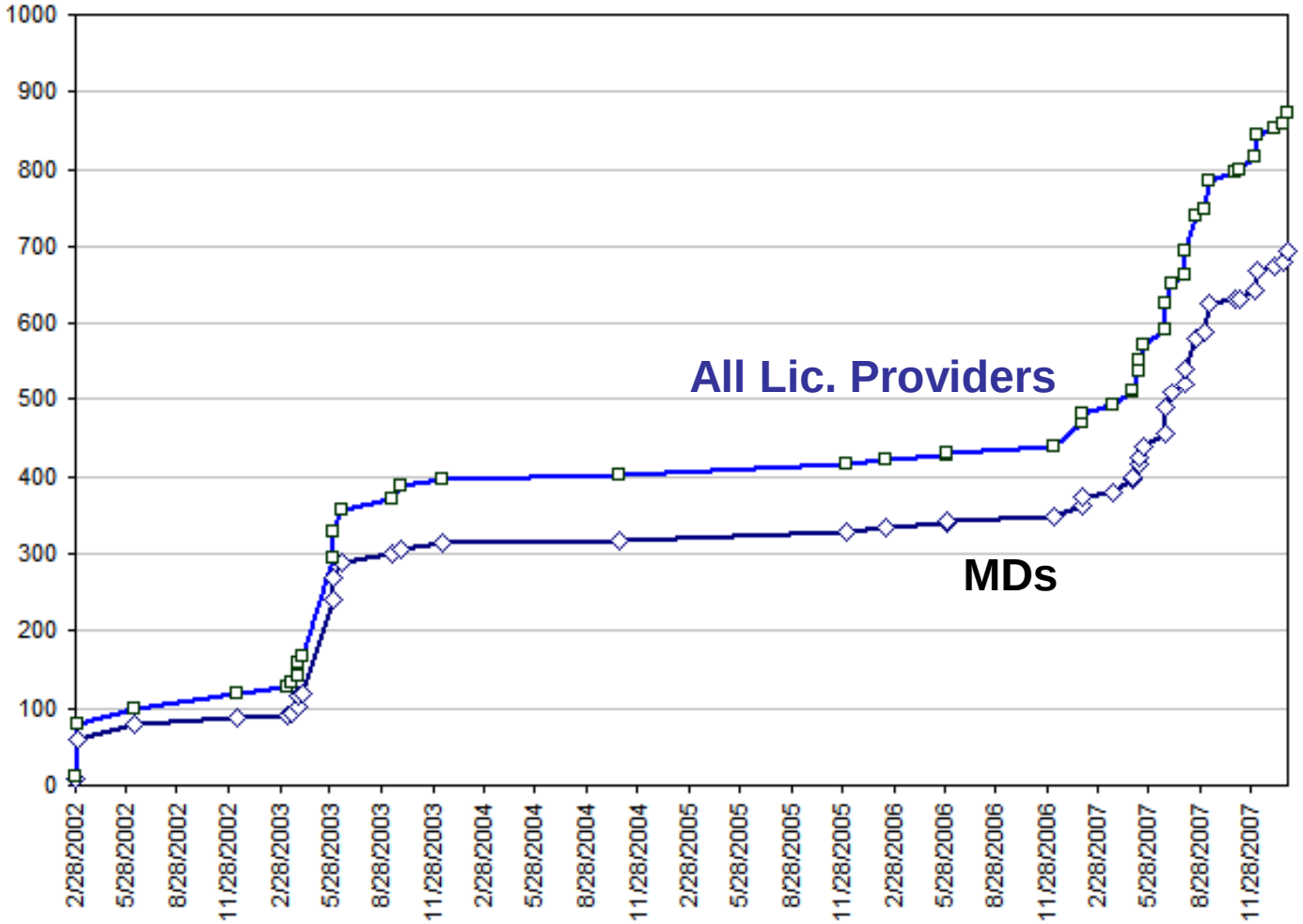


Activity – Mar '08

- **32,365 sessions (log ins)**
- **6,490 requests**



Provider adoption (March 2008)

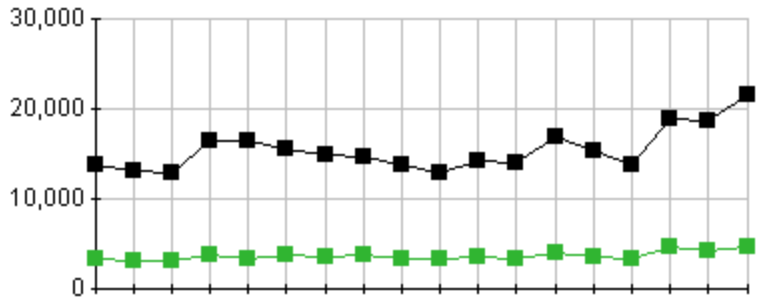


(As of Feb 2008)

Site-specific transactions

March 2008

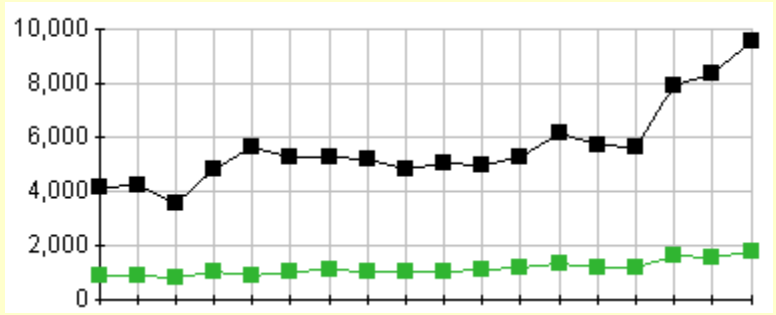
MGH



21,472 sessions

4,650 requests

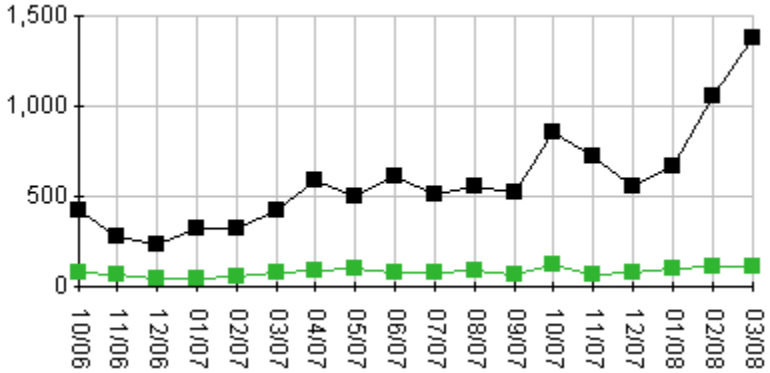
BWH



9,496 sessions

1,730 requests

DFCI

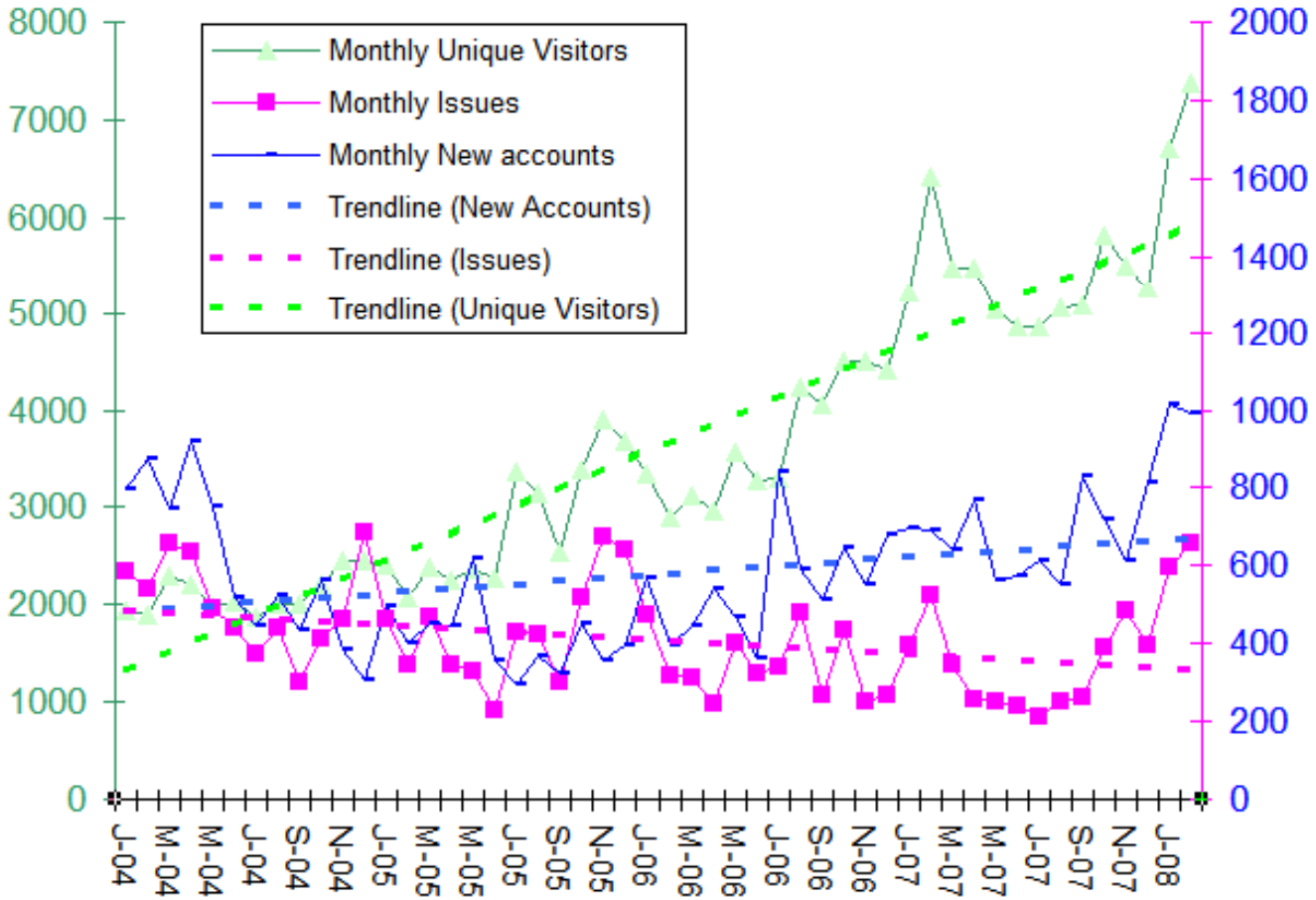


1,375 sessions

106 requests

Support issues

13K → 41K *Total accounts*



Trendlines show:

High growth in use, with modest growth in support issues

Lab Results rollout

- **Live in production since September, 2006**
  - 30 practices currently offer this feature to patients
  - 89% of patients have access today
  - Remaining practices are discussing when to offer this
- **Patients LOVE it! Many examples of positive feedback**
  - #1 patient complaint: where are the rest of my labs?
- **MDs/staff have not reported increased workload or patient anxiety associated with turning this On**
- **Benefits:**
  - Ensure all results are available; Avoid needless calls from patients asking for lab results; Avoid unnecessary delays in sharing results with the patient
  - Patients can access results when and where they find it convenient
  - CRICO (malpractice insurer) believes it is “safe practice”
- **Process for content approval**
  - PG Clinical Expert Panel recommends, and Clinical Content Committee approves; One “master list” across Partners

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Lessons Learned

- **Patients love it!**
  - Appreciate greater access; don't send high volume of online messages
- **Provider concerns – resolve with experience**
  - Concerns: Will cost them time; Patients will be alarmed; Patients will be confused
- **Barriers**
  - Marketing, preconceptions, workflow challenges, lack of incentives
- **Varied levels of use of these technologies**
  - Among patient and practices

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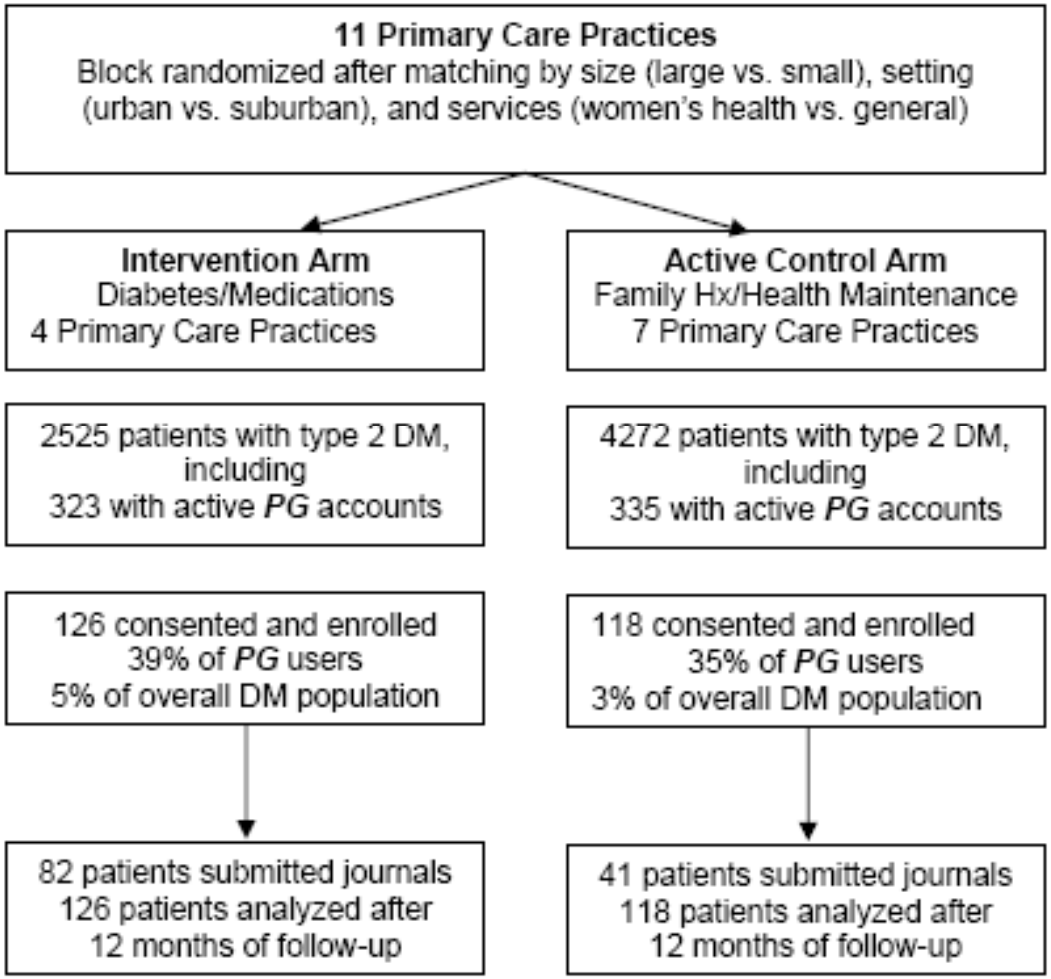
RCT: Practice-linked PHR for Type 2 Diabetes1

- **Primary care RCT in 11 clinics, over 1 year**
  - 244 patients with diabetes, mean age 56, 54% at goal for HbA1c (<7.0)
- **Intervention (126 participants)**
  - Patients with diabetes received online diabetes journals 2 weeks before a visit, via Patient Gateway
  - Invited to review their LMR medications and diabetes care measures
  - Could electronically submit information to their PCP for discussion during a visit
- **Controls (118 participants)**
  - Active controls received Patient Gateway and a non-diabetes journal (Health maintenance, Family history)
- **Outcomes**
  - Looked at HbA1c, cholesterol, BP, medication use, other process and survey measures

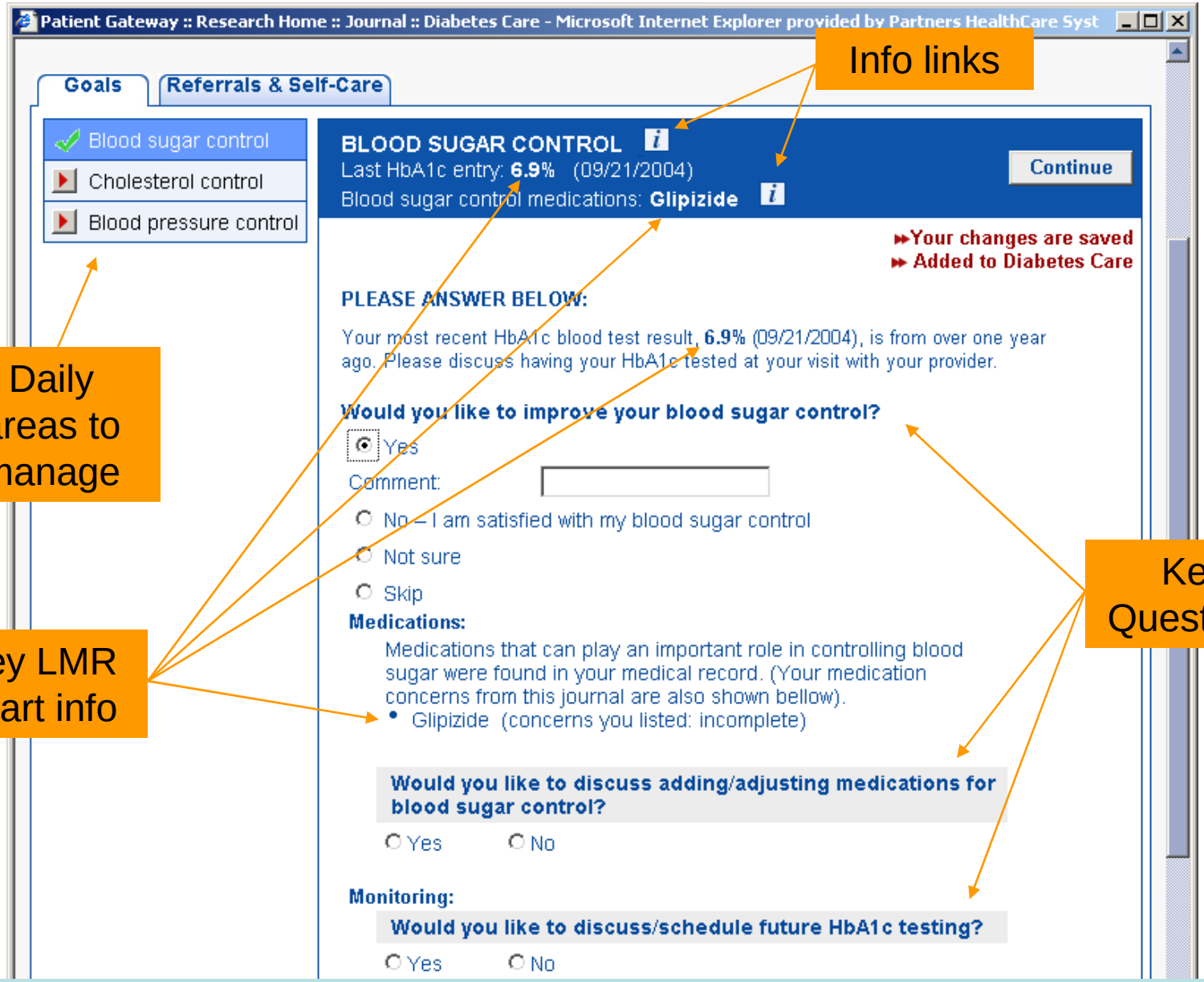
[1]*Grant RW, Wald JS, Schnipper JL, Gandhi TK, Poon EG, Orav EJ, Williams DH, Volk LA, Middleton B. Practice-linked Online Personal Health Records for Type 2 Diabetes: A Randomized Controlled Trial. Arch Int Med 2007, in press.*

RCT flow diagram



Grant RW et al. Practice-linked Online Personal Health Records for Type 2 Diabetes: A Randomized Controlled Trial. Arch Int Med 2007, in press.

Diabetes Pre-visit Journal



Grant RW et al. Practice-linked Online Personal Health Records for Type 2 Diabetes: A Randomized Controlled Trial. Arch Int Med 2007, in press.

Diabetes Pre-visit Journal Report

DIABETES CARE:

Goals:

Blood sugar control	Is satisfied; **Wants to discuss medications; Wants to discuss HbA1c testing**
Cholesterol control	***Not sure about improving; Wants to discuss medications; Wants to discuss cholesterol testing**
Blood pressure control	***Would like to improve;** Doesn't want to discuss medications; Doesn't want to discuss blood pressure monitoring

Referrals & Self-Care:

Eye care	**Would like to discuss; Would like a referral;**
Foot care	Doesn't want to discuss; Doesn't want a referral;
Nutrition	Not sure about discussing; Not sure about a referral to a nutritionist;
Exercise program	**Would like to discuss;**
Smoking cessation	(Skipped)
Daily aspirin	**Would like to discuss;** Already takes aspirin; Not allergic to aspirin;

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Patient activation

Over half of intervention patients said they wanted to improve their diabetes management.

"I would like to improve my…"

Blood sugar control:	**51%**
Blood pressure control:	**32%**
Cholesterol control:	**28%**

Grant RW et al. Practice-linked Online Personal Health Records for Type 2 Diabetes: A Randomized Controlled Trial. Arch Int Med 2007, in press.

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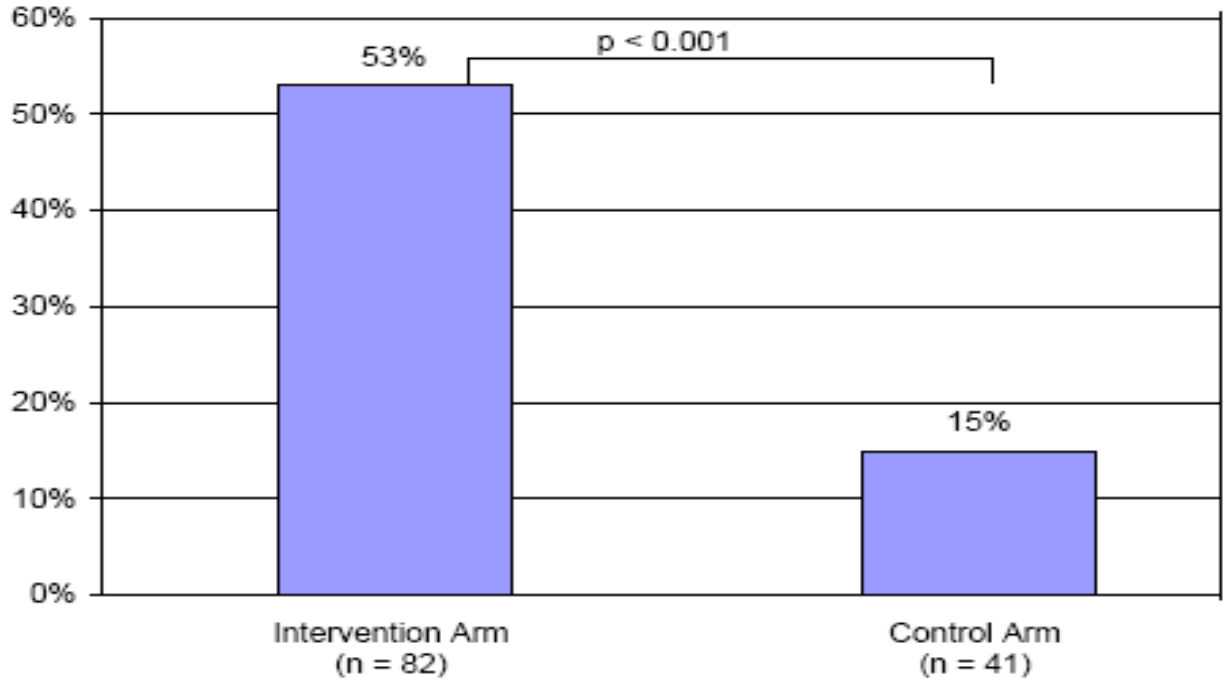
More medication changes in visits after diabetes journal submission



Grant RW et al. Practice-linked Online Personal Health Records for Type 2 Diabetes: A Randomized Controlled Trial. Arch Int Med 2007, in press.

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Diabetes RCT: Conclusions

- **Intervention use appears to improve diabetes care by reducing barriers to medication change at the clinic visit**
  - More medication regimen changes in visits subsequent to diabetes journal submission than other journal submission
  - Trend (non-significant) toward lower HbA1c among intervention patients with baseline HbA1c > 7.0

- **Caveats**
  - Small percentage of patients with diabetes participated in the study
  - Study participants were young, white, commercially insured, and closer to HbA1c goal (7.0) than non-participating subjects
  - Intervention group HbA1c did not improve more than controls

Grant RW et al. Practice-linked Online Personal Health Records for Type 2 Diabetes: A Randomized Controlled Trial. Arch Int Med 2007, in press.

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The Platform Model of Personally Controlled Health Records

Presented by:
Kenneth Mandl
Children's Hospital Boston

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Hospitals do not have a history of sharing information

- Proprietary
- Perceived competition
- Privacy
- Health Insurance Portability and Accountability Act
- No dedicated resources to do so

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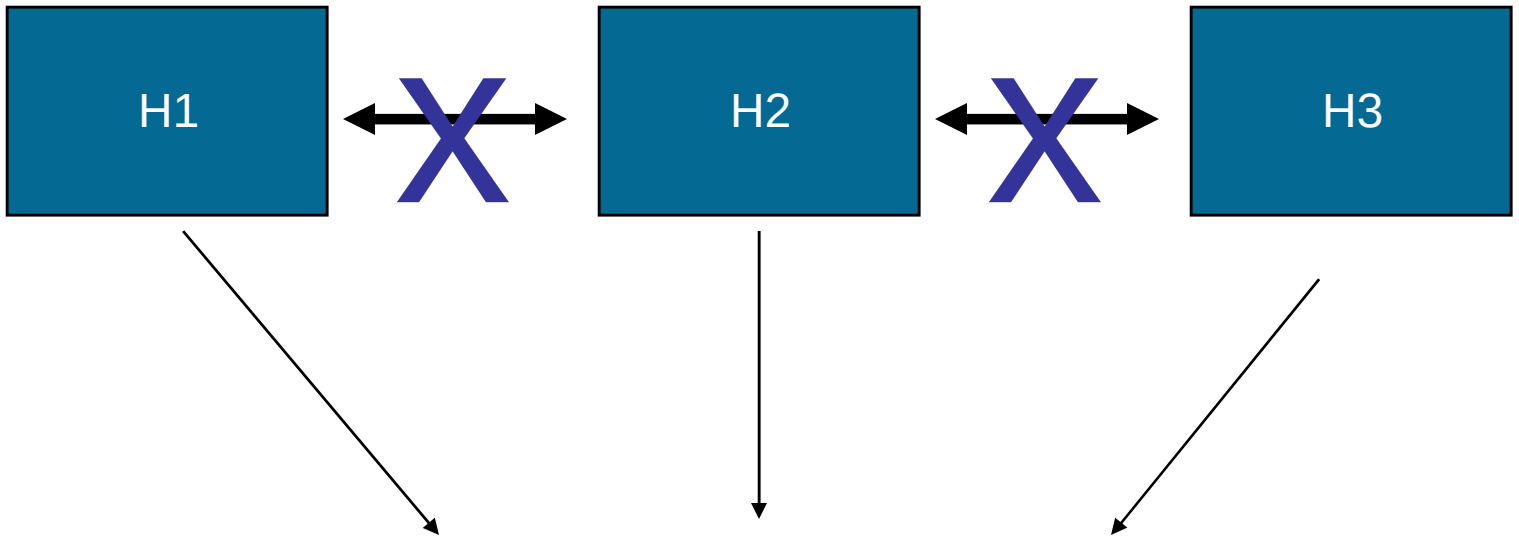
The patient has rights to request the record



May I please have my record?

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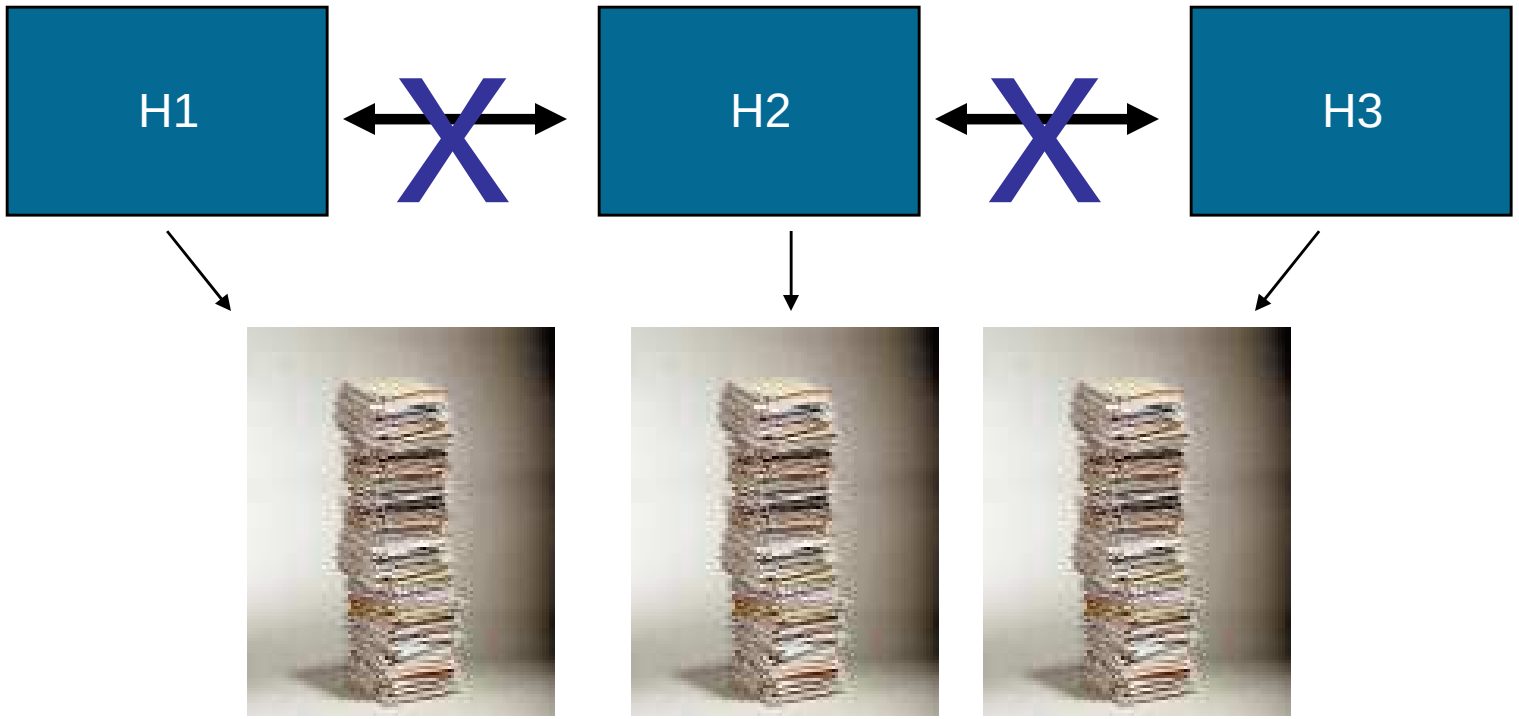
Currently . . .



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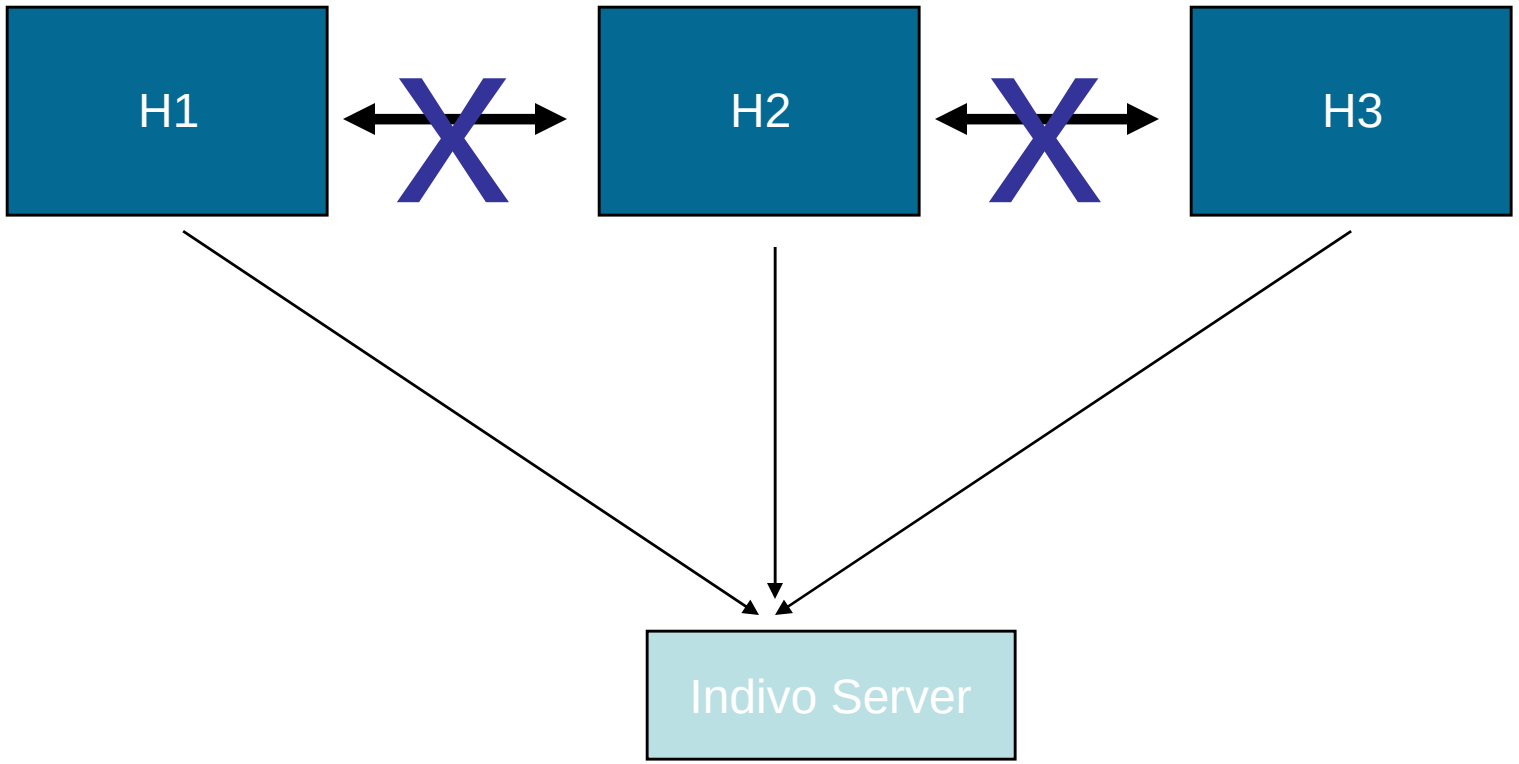
What if we gave patients a tool to request their records electronically?



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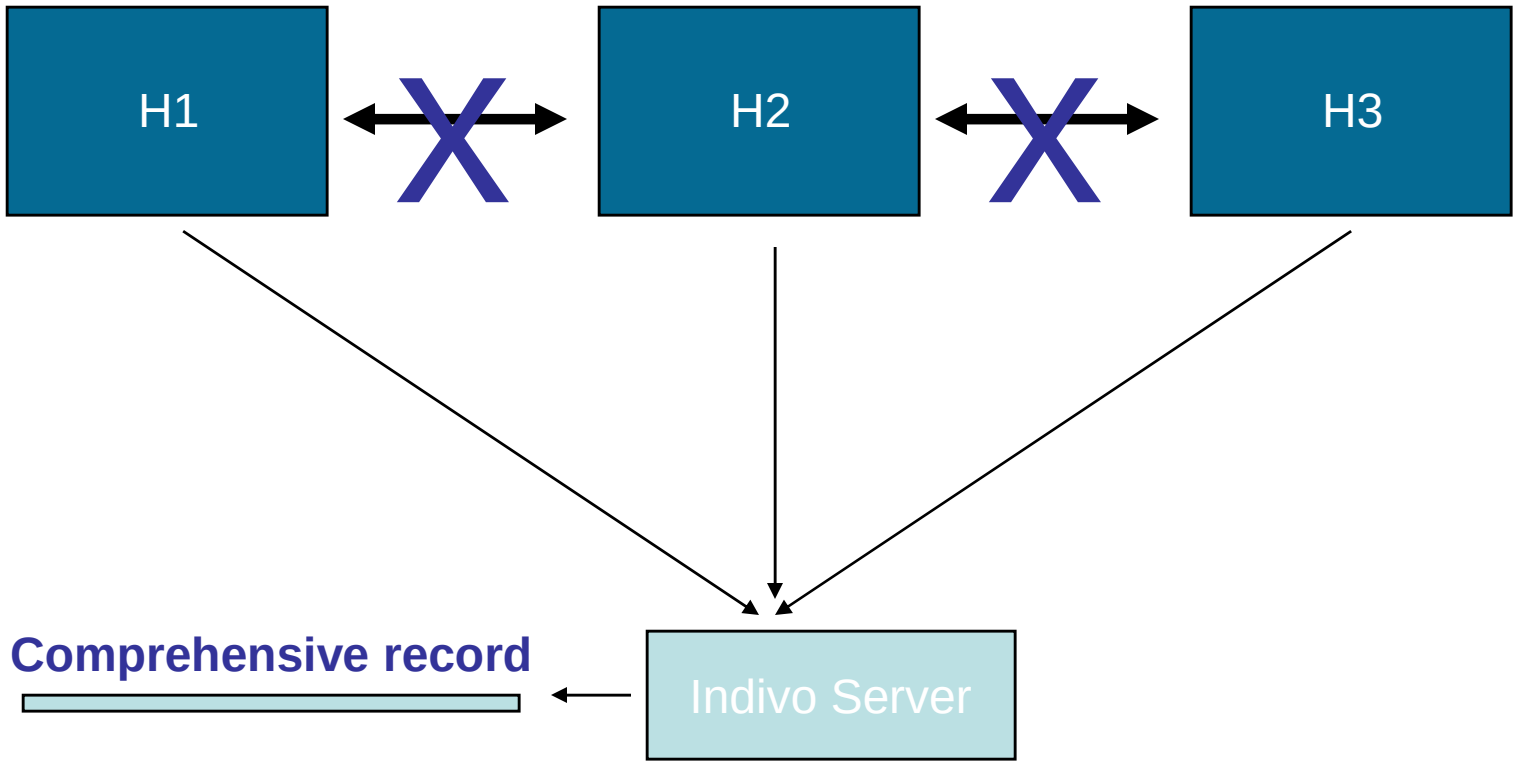
And create a personal health record?



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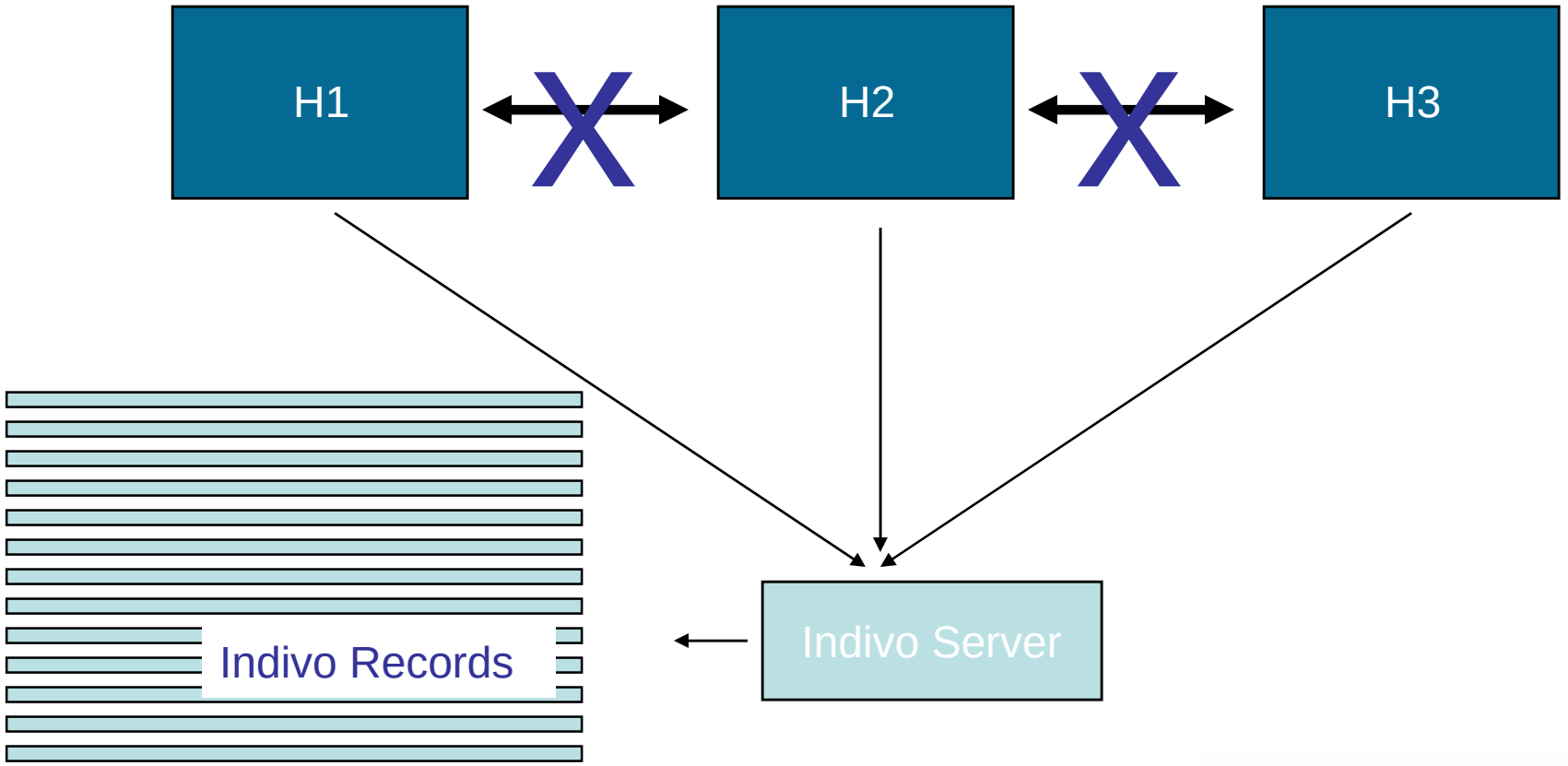
The collection of these records is a population health database



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Personally Controlled Health Records

- A container to store and share your personal health information
- A “quicken for health care”
- A “health bank” account
- Provides a “virtual medical home” for patients

BMJ

- **A PCHR stored all of an individual's medical history in a container with**
  - patient control
  - interoperability
  - open standards
  - rules to protect patients

Information in practice

Public standards and patients' control: how to keep electronic medical records accessible but private

Kenneth D Mandl, Peter Szolovits, Isaac S Kohane

BMJ. 2001;322:283-7.

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Patient role

- **Patients can**
  - access the record
  - grant access to others
    - specific to their role
    - of selected portions of the record
  - store their record in a location of their choice
  - annotate in the record (but not delete)

Rely on individual rights

- Confront privacy head on by exercising individual rights to information
- **The patient is the integrator of his/her own medical record**

Microsoft
HealthVault
BETA

dossia

Google

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Now your health information is at your fingertips, 24/7.

Sign up for a MyChildren's account at **mychildrens.org**

Use our quick, easy, and secure Web site to:

- Manage appointments
- Send a secure message to your clinician
- Update insurance information
- Pay bills online
- View your Indivo™ personally controlled health record, which includes measurements from clinic visits, lab results, immunizations, and more.

To get started, you need:

- **Medical Record Number**
  Simply ask for it during your visit at the clinic front desk or go to mychildrens.org to receive it by mail.

  Medical Record Number: _____

- **Account invoice number** or **date of last visit**

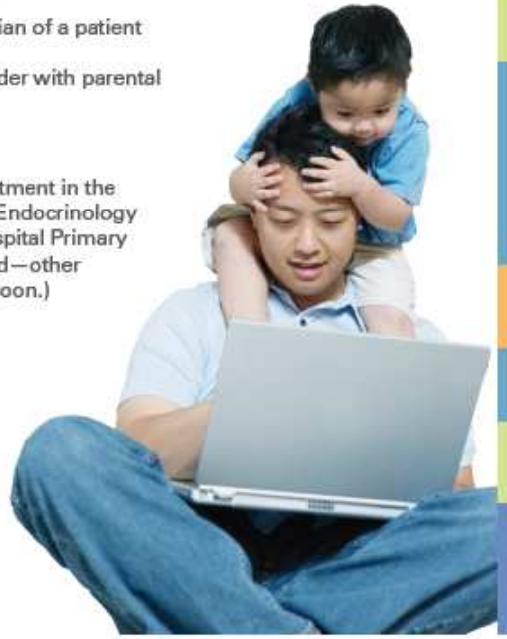
Now you can go to mychildrens.org and sign up for a MyChildren's account.

You're eligible if you're:

- A parent or legal guardian of a patient
- A patient over age 18
- A patient age 13 and older with parental consent

And

- A patient receiving treatment in the Myelodysplasia Clinic, Endocrinology Clinic, or Children's Hospital Primary Care Center. (Stay tuned—other programs are coming soon.)



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Openness

Open Systems

Can be extended to provide new capabilities

Open Standards

Allows open systems to exchange information; produces efficiencies

Open APIs

Allows building of applications on top of open systems and using open standards

Open Source

Allows compatible deployments

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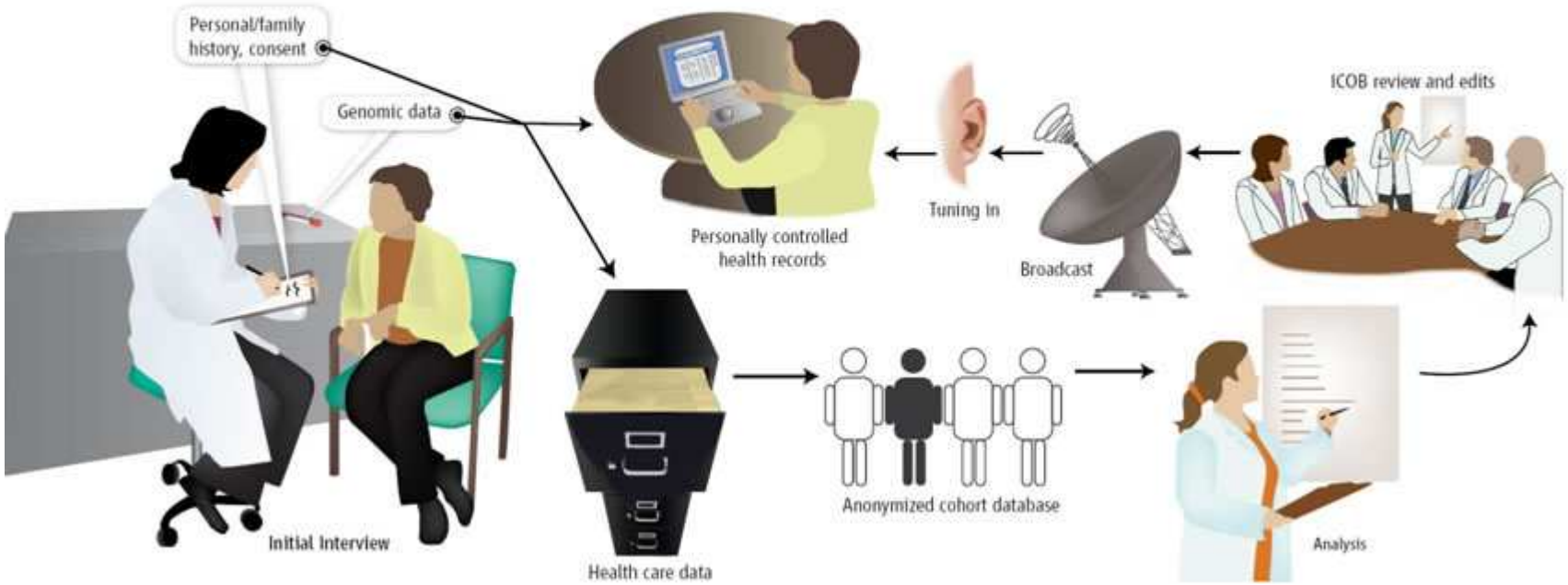
A research paradigm



Science 2007

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Challenges

- Agreement on data standards
- Data availability
- CLIA
- Data on paper
- User authentication

Selected Bibliography

Mandl KD, Szolovits P, Kohane IS. Public standards and patient control: how to keep electronic medical records accessible but private. BMJ 2001; 322:283–7.

Riva A, Mandl KD, Oh DH, Szolovits P, Kohane IS. The Personal Internetworked Notary and Guardian. International J Am Med Inform Assoc 2001; 62(1): 2–40.

Kohane IS, Mandl KD, Taylor PL, Holm IA, Nigrin DJ, Kunkel LM. MEDICINE: Reestablishing the Researcher-Patient Compact. Science. May 11, 2007 2007;316(5826):836-837.

Simons WW, Mandl KD, Kohane IS. The PING Personally Controlled Electronic Medical Record System: Technical Architecture. J Am Med Inform Assoc. January-February 2005;12(1):47-54.

Sax U, Kohane I, Mandl KD. Wireless Technology Infrastructures for Authentication of Patients: PKI that Rings. J Am Med Inform Assoc. May-Jun 2005;12(3):263-268.

Halamka JD, Mandl KD, Tang PC. Early experiences with personal health records. J Am Med Inform Assoc 2008;15(1):1-7.

Mandl KD, Simons WW, Crawford WC, Abbett JM. Indivo: a personally controlled health record for health information exchange and communication. BMC Med Inform Decis Mak 2007;7:25.

Bourgeois F, Simons W, Olson K, Brownstein J, Mandl K. Evaluation of influenza prevention in the workplace using a personally controlled health record. J Med Internet Res. 2008;10(1)e5:1-11.

Disclosure

Children's Hospital Boston has a contract with dossia to produce open source PCHR software. Mandl receives support from Children's Hospital Boston to advise on the Dossia-CHB relationship.

Questions & Answers

Our Panel

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Jonathan Wald, Partners HealthCare

Kenneth Mandl, Children's Hospital Boston

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